

**Community Support Services for Persons with Serious Mental Illness in Iowa:
Consumer Survey Results**

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Introduction

Rural states such as Iowa face challenges in developing appropriate and comprehensive community based services for persons with serious mental illness. Because, organization of community based services in Iowa is primarily county based, it is difficult to assure consistency of service availability across the state due to variation in county population, resources, and priorities. The purpose of this study is to describe the use, access, and satisfaction of community support services of persons with serious mental illness in Iowa. A similar survey of case managers and family members was also carried out and the results of these studies are reported separately (Rohland, 1996; Rohland, 1996).

Background

Definition of Serious Mental Illness. In Iowa, serious mental illness (SMI) in adults is defined by: 1) a psychiatric treatment more intensive than outpatient care more than once in a lifetime; or 2) a single episode of continuous, structured, supportive residential care other than hospitalization. In addition, individuals defined as having a serious mental illness are more likely to be unemployable in a competitive work force, require financial assistance for out of hospital maintenance, have a severe inability to establish or maintain a personal support system, require help in basic living skills or exhibit inappropriate social behavior which results in demand for intervention by the mental health or judicial system.

Organization of Services. Iowa is a rural state with 99 counties and nine Metropolitan Statistical Areas (MSAs). Systems of mental health service organization in Iowa are primarily county based. Although the state provides accreditation to mental health centers and mental health providers, each county is responsible for the limited provision of services for persons with serious mental illness who have residence in their county. There are 33 community support programs (CSPs) which are supported by state funding, all of which are affiliated with a community mental health center (CMHC). Most counties (93/99) have an affiliation with a CMHC and there are 36 CMHCs in Iowa, (each with catchment areas of one to nine counties).

County Funding for Mental Health Services. In an analysis of all counties (n=99), urban counties spend almost two dollars more per capita on mental health services than do rural counties (\$29.02 versus \$26.15). They also spend a higher proportion of their budget on persons with SMI (70% versus 61%). Among rural counties, counties with a CMHC in their county spend almost ten dollars more per capita than counties that have an out of county affiliation with a CMHC (\$32.29 versus \$22.63). Counties with no CMHC and no affiliation with a CMHC spend an amount of money which is intermediate (\$27.01). The average proportion of the mental health budget that is spent on persons with serious mental illness is about the same for all rural counties regardless of whether a CMHC is present within the county or whether or not they have an affiliation with a CMHC, i.e., 58-64%.

Community Support Services. In 1977, the National Institute of Mental Health (NIMH) developed the concept of a community support system (CSS) as the basis for planning and organizing comprehensive, community based, services for persons with serious mental illness (Stroul,

1988). The NIMH model of community support has ten essential service components defined as necessary in order to provide a continuous, comprehensive system of care for persons with serious mental illness. Community support services are intended to be coordinated by case management, variably defined as a single person, team, or agency. In addition, case management was intended to monitor the adequacy and appropriateness of services.

The ten components of community support that were specified by the NIMH include:

1. Crisis Response Services (crisis telephone services, walk-in crisis services, mobile crisis outreach services, crisis residential service, inpatient services)
2. Mental Health Treatment (diagnostic evaluation, supportive counseling, medication management, substance abuse services)
3. Income Support and Entitlements
4. Protection and Advocacy
5. Physical Health and Dental Services
6. Housing (supportive housing, residential assistance for homeless mentally ill persons)
7. Psychosocial Rehabilitation (social and vocational)
8. Peer Support (self-help, consumer-operated services)
9. Identification and Outreach (client identification, outreach, transportation assistance)
10. Family and Community Support (support and assistance to families, support and education for the community)

Methods

Potential subjects were referred by case managers and community support program directors, the Iowa Coalition, and the Alliance for the Mentally Ill of Iowa (AMI). Case managers, community support program directors, the Iowa Coalition, and affiliate presidents of AMI of Iowa were sent a description of the project and were asked to identify persons with serious mental illness who received services and who would be willing to complete this survey. A total of 1189 consumers was identified by these sources. Case managers identified 693 consumers; community support program directors identified 409; and AMI of Iowa identified 87 consumers. The contact person was sent an 11 page, 45 item survey to be given to the consumers that they had identified. Completed surveys were to be completed and returned in a self addressed, stamped envelope between February 1, 1995, and August 15, 1995. Two hundred sixty-nine completed surveys were received. Nearly one half of respondents indicated that they had required help in completing the questionnaire (121/264).

Consumers were asked to indicate whether they had needed and/or received any community support services over the past one year and, if used, their satisfaction with case management and each of the 10 components of community support services in their county. The instrument used was adapted from an earlier, unpublished survey (Friedrich, 1994) and was reviewed by a multidisciplinary team for content validity. The team consisted of nurses, psychiatrists, and representatives of the Alliance for the Mentally Ill (AMI), DHS, the Community Mental Health Centers Association, and case managers.

Results

A total of 269 responses was received from 1189 consumers (23%) who had been identified as potential subjects. The source and number of referrals for respondents was: 34 by the Alliance for the Mentally Ill of Iowa (AMI); 66 by case managers; and 169 were identified by Community Support Program staff. Over 80% of consumers that responded to the survey and who indicated

that they had used services reported satisfaction with all service components. However, the number of consumers who indicated that a service was used varied from 250/262 (95%) for mental health treatment to 104/241 (43%) for housing services. Of responding consumers, 49 counties were represented (41 rural and 8 urban); 38% (101/269) responses were from consumers who lived in urban counties and 63% (168/269) lived in rural counties.

Characteristics of Responding Consumers

Demographic Characteristics (Age, Gender, Marital Status, Education, and Ethnicity). The average age of consumer respondents was 43 years with a range from 20 to 81 years. The majority of respondents were female (57%) and most (also 57%) had never been married. About one quarter of respondents were divorced or separated, and 12% were currently married or living together.

The educational level of 267/269 respondents is summarized in Table 1. Most respondents (79%) had a high school education or greater. Nearly one-half of respondents, (45%) had at least some college education.

Table 1: Educational level of Consumers (n=267)

Graduate or Professional Degree	Some Graduate School	College Graduate	Some College	High School or Equivalent	Some High School	Eighth Grade or Less
14 (5%)	9 (3%)	20 (8%)	78 (29%)	90 (34%)	35 (13%)	21 (8%)

Psychiatric Diagnosis. Respondents were asked to identify all their current psychiatric diagnoses and to indicate the one diagnosis that caused them the most difficulty in day-to-day life. Respondents indicated that they had an average of 1.6 diagnoses each, 3 respondents did not indicate a diagnosis. Seventy-four percent of respondents (199/269) identified a single diagnosis that they considered to be the main source of their disability, the most common being schizophrenia (29%); depression (27%); and bipolar disorder (13%). Responses are summarized in Table 2. A small number of respondents indicated that they had a co-occurring substance abuse problem (35/268 or 13%). In addition, 60% of consumers reported that they had a medical problem in addition to their psychiatric illness.

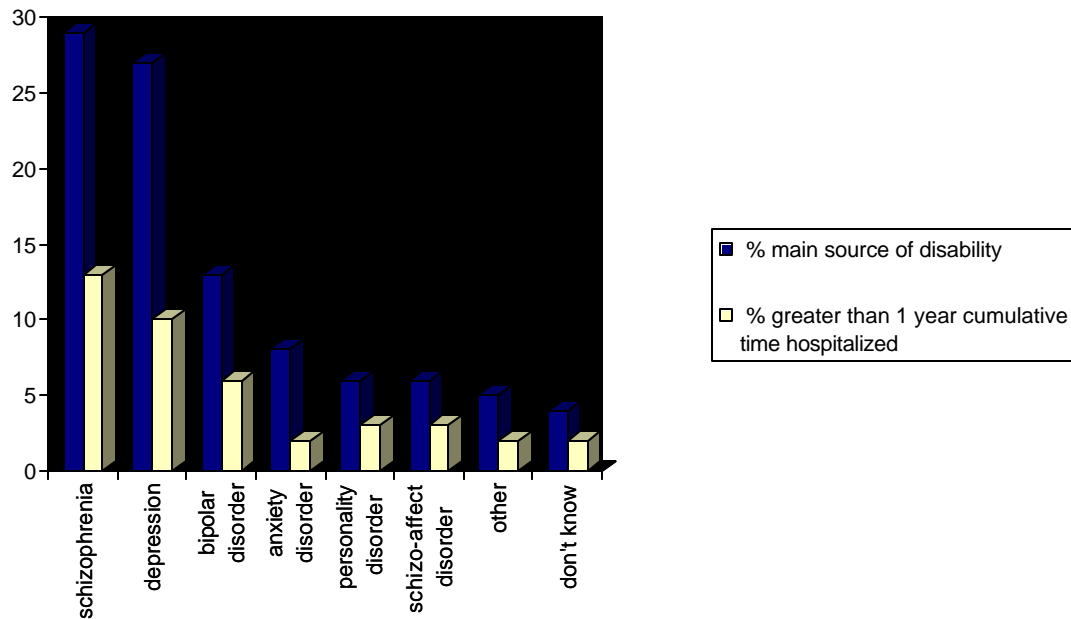
Duration of Illness and History of Hospitalization (Table 2). The number of years ill with a psychiatric illness reported by consumers ranged from 1 to 47 years, with an average of 18 years. Since becoming ill, about 40% of respondents reported cumulative hospitalization of more than 1 year (for treatment of a psychiatric illness) and nearly 60% had been hospitalized from 1 to 12 months. The relationship between duration of illness and diagnosis is illustrated in Figure 1.

Table 2: Main Source of Disability

Diagnosis	Main Source of Disability n=199	Duration of Illness (average number years)	Cumulative time hospitalized (% respondents indicating greater than one year)
schizophrenia	29%	20	43%

depression	27%	17	37%
bipolar disorder	13%	20	42%
anxiety disorder	8%	17	19%
personality disorder	6%	13	42%
schizo-affective disorder	6%	20	46%
other	5%	23	40%
don't know	4%	23	57%
eating disorder	2%	15	25%
dementia	1%	20	0%

Figure 1: Main Source of Disability (diagnoses) and Cumulative Time Hospitalized (greater than 1 year)



Employment. Nearly 70% of respondents were not currently employed (180/262).

Housing. Consumers were asked with whom they lived. Of the 256 who responded to this question, 54% lived alone, 15% lived with a spouse or significant other, 18% lived in a supervised group situation, 9% lived with parents, and 5% with other relatives or friends. Consumers were also asked where they currently live and this question was answered by 245 respondents. Fifty-nine per cent of the respondents indicated they live in their own home or apartment and nearly one half of them (47%) received in-home staff visits. A smaller proportion of respondents lived in residential care (16%), or parental home (7%). Of those who lived in their parents' home 5/13 received in-home staff visits. Shelter for the homeless or living in the streets were not indicated as a current living arrangement by any of the respondents.

Consumers were asked the type of housing they thought would be best for them, even if it was not currently available. Of the 215 persons who responded to this question, 64% indicated that they would like to be in their own home or apartment. Stated preferences were approximately equally divided between with in-home staff visits (72/137) versus without (65/137). Of the 148 responses to the question, the most common reasons given by consumers for not living in the housing that they thought was best for them was that they could not afford it (20%); they were not willing to leave their current housing (19%); there was a long waiting list (16%); and that the housing did not exist locally (13%). Other responses were that their doctor, parents, or courts wouldn't let them (11%) or they didn't know (10%).

Mental Health Care Expenses. Respondents were asked to indicate all their sources of payment for mental health care. The most common sources of payment indicated was Medicaid (27%), Medicare (26%), and SSI or SSDI (22%). Private insurance (group insurance through employer, individual health insurance, or dependent coverage under family's health insurance) was listed by only 7% of respondents.

Case Management Services. About 75% of respondents (191/260) indicated that they currently had a case manager. Approximately 40% of respondents indicated that they met with or talked to their case manager at least once a week, and about 60% indicated frequency contact of once a month or less.

County of Legal Settlement. Over 85% (232/267) of the respondents indicated that they lived in their county of legal residence. About 10% (25/267) of respondents reported that they did not, and about 4% (10/267) didn't know.

Commitment Status. Of the 264 respondents who indicated their commitment status, 23% were on out-patient commitment, 61% were not, and 15% did not know.

Service Component Satisfaction

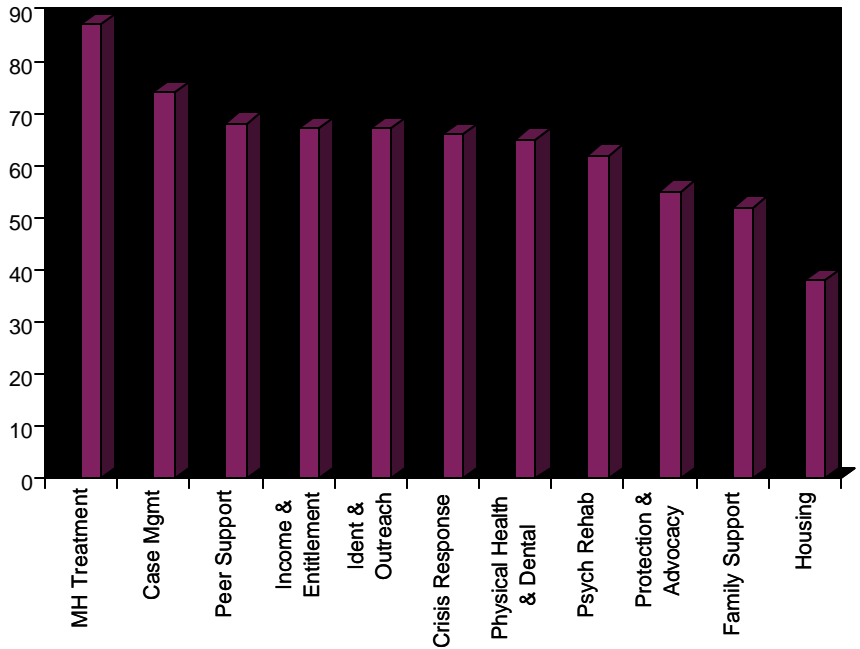
Satisfaction of each of the ten components was assessed by asking consumers how satisfied they were with services within each of the 10 service components. They were asked to rate satisfaction by using a 4 point scale from 1 (very satisfied) to 4 (very dissatisfied). They could also indicate that the service was not used over the past year. Responses of "very satisfied" or "somewhat satisfied" were combined and compared to responses of "somewhat dissatisfied" or "very dissatisfied" to measure of service satisfaction by consumers. Responses are summarized in Table 3. The satisfaction with service components was uniform and over 80% for all components. The reported use of services was more variable and ranged from 95% for mental

health treatment to 43% for housing. The proportion of respondents who used and were satisfied with each service component was calculated and illustrated in Figure 2. Most respondents (87%) reported that they had both used and were satisfied with mental health treatment. This contrasts to only 38% of respondents who had both used and expressed satisfaction with housing services.

Table 3: Assessment of Service Component Satisfaction by Consumers

Service Component	Consumer Satisfaction		
	number responding	service not used over past one year	satisfaction
I. Crisis Response	255	25% (63/255)	88% (169/192)
II. Mental Health Treatment	262	5% (12/262)	92% (230/250)
III. Income and Entitlement	249	23% (56/249)	87% (167/193)
IV. Protection and Advocacy	246	44% (107/246)	84% (116/139)
V. Physical Health and Dental	253	25% (62/253)	87% (167/191)
VI. Housing	241	57% (137/241)	88% (91/104)
VII. Psychosocial Rehabilitation	253	25% (62/253)	83% (158/191)
VIII. Peer Support	248	24% (59/248)	89% (169/189)
IX. Identification and Outreach	250	26% (66/250)	90% (165/184)
X. Family Support	249	40% (99/249)	86% (129/150)
XI. Case Management	252	18% (45/252)	90% (186/207)

Figure 2: Proportion of Respondents Who Reported Use and Satisfaction with Service Components



Service Access, Need, and Utilization

Respondents were asked to indicate whether they had needed and/or received specific types of services within each service component. Consumers were asked to indicate “yes”, “no”, or “don’t know” if they needed specific services from within each of the individual service components during the past one year period and to also indicate “yes”, “no”, or “don’t know” if those services were received. The following variables were defined and calculated from this information. Results for specific services within each of the ten service components are described in the following section and summarized in Tables 4 - 14.

Access to Services = the proportion of respondents who indicated that they had received a service out of the population who indicated that they had needed that service. This is used as a measure of the ability to obtain a service by those persons who perceive a need for that service.

Service Need = the proportion of respondents who indicated that they needed a service out of the population who indicated that they had received that service. This is used as a measure of overuse of a service (or unwanted service use) from the consumer perspective i.e., that a service was received when it was not perceived to be needed by the consumer.

Service Utilization = the proportion of respondents who indicated that they had both needed and received a given service out of the population of all survey respondents. This was taken as an estimate of the desired utilization of all available services by all consumer respondents. It does not measure the availability of any given service or whether or not the use of that service is appropriate or effective for any individual or groups of individuals.

I. Crisis Response (Table 4). Service utilization ranged from 5% for mobile crisis unit to 38% having phone contact with a counselor. Nearly one third of respondents indicated that they had used the emergency room at a hospital over the past one year period. Interestingly, the service with the lowest reported access was phone contact with a counselor (55%). The services with the highest reported access (88% each) were emergency services, walk-in crisis support at a CMHC, outpatient psychiatric clinic emergency services, and hospital emergency room visits. There was no evidence of service overuse (i.e., that a service was received when it was not needed) from the perspective of the consumer respondents for crisis response services.

Table 4: Service Component I. Crisis Response

	Service Component	Service Access	Service Need	Service Utilization
a.	24 hour crisis telephone service	68/86 (79%)	68/74 (92%)	68/269 (25%)
b.	walk-in crisis support services at a community mental health center	74/98 (88%)	74/77 (96%)	74/269 (28%)
c.	phone contact with counselor during the week	101/115 (55%)	101/109 (93%)	101/269 (38%)
d.	mobile crisis unit that comes to your home	12/22 (70%)	12/12 (100%)	12/269 (5%)
e.	short term crisis residential services	35/50 (81%)	35/38 (92%)	35/269 (13%)
f.	outpatient psychiatric clinic emergency services	67/83 (88%)	67/68 (99%)	67/269 (25%)
g.	hospital emergency room	86/98 (88%)	86/90 (96%)	86/269 (32%)
h.	police department services	37/44 (84%)	37/38 (97%)	37/269 (14%)
i.	emergency visit to family doctor	54/65 (83%)	54/56 (96%)	54/269 (20%)

II. Mental Health Treatment (Table 5). Service utilization ranged from 10% for family therapy to 63% for individual counseling. There was no apparent receipt of unneeded services from the consumer perspective (i.e., services, when received, were reported as needed by 90% or more of the respondents). Access to services ranged from 68% for family therapy to 89% for monitoring symptoms of mental illness.

Table 5: Service Component II. Mental Health Treatment

	Service Component	Service Access	Service Need	Service Utilization
a.	help with medication problems (for example, side effects)	145/172 (84%)	145/146 (99%)	145/269 (54%)
b.	help with taking medications as directed	83/97 (86%)	83/87 (95%)	83/269 (31%)
c.	individual counseling	170/196 (87%)	170/172 (99%)	170/269 (63%)
d.	group therapy	94/114 (83%)	94/100 (94%)	94/269 (35%)
e.	family therapy	27/40 (68%)	27/28 (96%)	27/269 (10%)
f.	monitor symptoms of mental illness	148/166 (89%)	148/151 (98%)	148/269 (55%)
g.	education in coping skills	147/181 (81%)	147/150 (98%)	147/269 (54%)
h.	education regarding signs of relapse	108/134 (81%)	108/109 (99%)	108/269 (40%)
i.	education concerning mental illness	136/166 (82%)	136/143 (95%)	136/269 (51%)
j.	frequent in-home staff visits	83/105 (79%)	83/87 (95%)	83/269 (31%)
k.	in-home staff visits (for example, Visiting Nurse Association)	68/88 (77%)	68/70 (97%)	68/269 (25%)

III. Income Support and Entitlements (Table 6). Service utilization was between 25% and 50% for all services within this component. There was no apparent receipt of unneeded services from the consumer perspective (i.e., services, when received, were reported as needed by 90% or more of the respondents). Access to services within this component was between 82% and 88%.

Table 6: Service Component III. Income Support and Entitlements

	Service Component	Service Access	Service Need	Service Utilization
a.	assistance with obtaining income supports (for example, SSI, SSDI)	112/127 (88%)	112/115 (97%)	112/269 (42%)
b.	assistance with obtaining health care financing (for example, Medicaid, Medicare, private health insurance)	105/121 (87%)	105/107 (98%)	105/269 (39%)
c.	assistance with obtaining welfare benefits (for example, food stamps, Aid to Families with Dependent Children, etc.)	71/85 (84%)	71/77 (92%)	71/269 (26%)
d.	housing assistance	82/100 (82%)	82/85 (97%)	82/269 (31%)

IV. Protection and Advocacy (Table 7). Service utilization was 26% or less for services in this component. There was no apparent receipt of unneeded services from the consumer perspective (i.e., services, when received, were reported as needed by 90% or more of the respondents). Access rates for services within this component were approximately 70%.

Table 7: Service Component IV. Protection and Advocacy

	Service Component	Service Access	Service Need	Service Utilization
a.	information about your legal rights	69/94 (73%)	69/72 (96%)	69/269 (26%)
b.	assistance with commitment process	28/41 (68%)	28/30 (93%)	28/269 (10%)
c.	assistance in contacting agencies about questions or complaints	66/91 (73%)	66/68 (97%)	66/269 (25%)

V. Physical Health and Dental Services (Table 8). Low rates of service utilization (5%-8%) were reported for help in abstaining from substances (alcohol, drugs, or cigarettes) and for assistance with pregnancy prevention. Fourteen percent of respondents received help regarding prevention of sexually transmitted diseases and AIDS. Nearly one half of respondents needed and received assistance in obtaining treatment for medical illnesses. There was no apparent receipt of unneeded services from the consumer perspective (i.e., services, when received, were reported as needed by 90% or more of the respondents). Access to services ranged from 58% for assistance with smoking cessation to 86% for assistance with prevention of sexually transmitted diseases and AIDS. Access to medical treatment was reported by 85%.

Table 8: Service Component V. Physical Health and Dental Services

	Service Component	Service Access	Service Need	Service Utilization
a.	assistance obtaining medical treatment for illnesses other than mental illness	116/137 (85%)	116/118 (98%)	116/269 (43%)
b.	assistance obtaining dental services	76/104 (73%)	76/81 (94%)	76/269 (28%)
c.	assistance maintaining physical fitness	66/99 (67%)	66/69 (96%)	66/269 (25%)
d.	assistance with weight control	67/105 (81%)	67/70 (96%)	67/269 (25%)
e.	assistance with stopping the use of alcohol and/or drugs	21/26 (80%)	21/22 (96%)	21/269 (8%)
f.	assistance with pregnancy prevention	12/15 (80%)	12/13 (92%)	12/269 (5%)
g.	assistance controlling smoking	22/38 (58%)	22/24 (92%)	22/269 (8%)
h.	assistance with prevention of sexually transmitted diseases and AIDS	38/44 (86%)	38/38 (100%)	38/269 (14%)

VI. Housing (Table 9). Low rates of service utilization (22% or less) were reported for housing services. There was no apparent receipt of unneeded services from the consumer perspective except that only 78% of respondents who reported receiving help finding emergency housing also reported needing such help. Access was 96-100% for services in this component except that receiving help in finding emergency housing was only reported by 62% who reported needing it.

Table 9: Service Component VI. Housing

	Service Component	Service Access	Service Need	Service Utilization
a.	help finding housing that has services I need	49/67 (96%)	49/51 (96%)	49/269 (18%)
b.	help finding long-term, stable housing	52/68 (100%)	52/52 (100%)	52/269 (19%)
c.	help finding housing that I can afford	58/77 (100%)	58/58 (100%)	58/269 (22%)
d.	help finding emergency housing	18/29 (62%)	18/23 (78%)	18/269 (7%)

VII. Psychosocial Rehabilitation (Table 10). Rates of service utilization were low (25% or less) for psychosocial rehabilitation services with utilization of help with tasks of everyday living and supervision or help with managing money being somewhat higher (29% and 35%, respectively). There was no apparent receipt of unneeded services from the consumer perspective (i.e., services, when received, were reported as needed by 90% or more of the respondents). Service access ranged from 60% for help with finding volunteer work and 83% for supervision or help with managing money.

Table 10: Service Component VII. Psychosocial Rehabilitation

	Service Component	Service Access	Service Need	Service Utilization
a.	help with finding a job	68/96 (70%)	68/70 (97%)	68/269 (25%)
b.	help with keeping a job	54/77 (70%)	54/56 (96%)	54/269 (20%)
c.	help with job training	64/91 (70%)	64/67 (96%)	64/269 (24%)
d.	help with completing my education	37/58 (64%)	37/38 (97%)	37/269 (14%)
e.	help with finding volunteer work	31/52 (60%)	31/32 (97%)	31/269 (12%)
f.	help with tasks of everyday living (for example, laundry, housecleaning, preparing meals, shopping for groceries, etc.)	78/108 (72%)	78/81 (96%)	78/269 (29%)
g.	help with the use of public transportation	51/66 (77%)	51/52 (98%)	51/269 (19%)
h.	supervision or help with managing money	94/114 (83%)	94/98 (96%)	94/269 (35%)
i.	assistance in maintaining personal hygiene (for example, bathing, dressing, grooming)	38/50 (76%)	38/39 (94%)	38/269 (14%)

VIII. Peer Support (Table 11). Rates of service utilization were between 23% and 38% for all peer support services. There was no apparent receipt of unneeded services from the consumer perspective (i.e., services, when received, were reported as needed by 90% or more of the respondents). Access to services within this component ranged from 71% for help getting along with family to 83% for respondents who said that they had needed and received help in getting along with friends.

Table 11: Service Component VIII. Peer Support

	Service Component	Service Access	Service Need	Service Utilization
a.	help getting along with family	62/87 (71%)	62/65 (95%)	62/269 (23%)
b.	assistance with recreation and leisure activities	101/126 (80%)	101/103 (98%)	101/269 (38%)
c.	help with making friends	78/107 (73%)	78/79 (99%)	78/269 (29%)
d.	help getting along with friends	74/89 (83%)	74/77 (96%)	74/269 (28%)
e.	help with spouse or girlfriend or boyfriend relationships	65/80 (81%)	65/67 (97%)	65/269 (24%)
f.	help with day to day social interactions	86/107 (80%)	86/88 (98%)	86/269 (32%)

IX. Identification and Outreach (Table 12). The service with the lowest reported utilization rate was outreach services to individuals who decline a formal treatment program (9%). The highest rate of utilization (44%) was reported for information about service availability and referral to agencies. There was no apparent receipt of unneeded services from the consumer perspective (i.e., services, when received, were reported as needed by 90% or more of the respondents). Access to services ranged from 78% for outreach services to individuals who decline a formal treatment program to 86% of persons receiving referral to agencies for services.

Table 12: Service Component IX. Identification and Outreach

	Service Component	Service Access	Service Need	Service Utilization
a.	information about services available	119/152 (78%)	119/119 (100%)	119/269 (44%)
b.	referral to agencies for services	119/139 (86%)	119/119 (100%)	119/269 (44%)
c.	coordination of community services	90/113 (80%)	90/90 (100%)	90/269 (34%)
d.	transportation to the services	92/111 (83%)	92/94 (98%)	92/269 (13%)
e.	outreach services to clients who miss appointments or discontinue medication	36/49 (73%)	36/38 (95%)	36/269 (23%)
f.	home visits for clients on a downhill turn	62/82 (76%)	62/62 (100%)	62/269 (23%)
g.	outreach services to individuals who decline a formal treatment program	23/32 (72%)	23/24 (96%)	23/269 (9%)

X. Family Support (Table 13). The service with the lowest reported utilization rate was identification of temporary caregivers so that family could get away (5%); utilization of referral to family therapy groups was also low (8%). The highest utilization rate for services in this category was 44% for education about the illness and medications. Access ranged from 55% for identification of temporary caregivers to 84% for education about the illness and medications. There was no apparent receipt of unneeded services from the consumer perspective, except that identification of temporary caregivers so that family could get away was reported as needed by only 86% of persons who reported receiving this service.

Table 13: Service Component X. Family Support

	Service Component	Service Access	Service Need	Service Utilization
a.	identification of temporary caregivers so your family could get away	12/22 (55%)	12/14 (86%)	12/269 (5%)
b.	referral to family support groups (for example, alliance for the mentally ill (AMI))	43/62 (69%)	43/45 (96%)	43/269 (16%)
c.	referral to family therapy groups	21/33 (64%)	21/22 (96%)	21/269 (8%)
d.	education about the illness and medications	118/141 (84%)	118/120 (98%)	118/269 (44%)
e.	assistance with handling daily problems related to psychiatric illness	101/127 (80%)	101/103 (98%)	101/269 (38%)
f.	involvement of family in treatment planning	56/80 (70%)	56/59 (95%)	56/269 (21%)

XI. Case Management (Table 14). Case management services were utilized by 26% to 56% of consumer respondents. There was no apparent receipt of unneeded services from the consumer perspective (i.e., services, when received, were reported as needed by 90% or more of the respondents). Access to case management services was reported to be from 76% for 87% for all types of services within this component.

Table 14: Service Component XI. Case Management

	Service Component	Service Access	Service Need	Service Utilization
a.	arrange for individualized services	115/133 (87%)	115/115 (100%)	115/269 (43%)
b.	make referrals to agencies (for example, visiting nurse association)	69/86 (80%)	69/70 (99%)	69/269 (26%)
c.	advocate on your behalf to programs and agencies	87/115 (76%)	87/88 (99%)	87/269 (32%)
d.	develop comprehensive treatment care plans	117/134 (87%)	117/119 (98%)	117/269 (44%)
e.	monitor your condition (for example, change in symptoms, mood)	151/176 (86%)	151/153 (99%)	151/269 (56%)

Additional Comments by Respondents

Ninety-five respondents provided open-ended comments that generally fell into 2 categories: comments about personal experiences with treatment and comments about the organization and availability of support services.

Other respondents specifically addressed the benefits that they had derived from a particular mental health care professional or agency, e.g., “I am very appreciative of the services I receive from by CSP worker and don’t know what would have happened to me without her support.”; “It is really important for me to have day treatment program...”; “Without the assistance of CSP services I would probably be living in a group or nursing home.”; “Our mental health clinic has a very caring staff and helps us very much.”

Some comments addressed the overall organization of support services.

- “How do I find these services. If you can help me, please do. I don’t know where to turn.”
- “All my needs are being taken care of.”
- “I wish xx had people that care and help me do the things I can’t and teach me how.”
- “...Can mental health services come to me, my town?”
- “I am an ‘in-betweener’. No services and all services. Because I don’t need all services, I end up getting no service help. I function well 47-49 weeks of the year. The other three to four weeks are pure hell. Its too bad people like me trying to make a transition out of the mental health system can’t get the supportive help we need. The current system is all or nothing.”
- “I feel there is a real need for more places like xx [transition center]. I hope there will always be funding for case management and other services for the seriously mentally ill.”
- “I think the community support network is great.”

- “I really depend on my CSP worker to help me to continue to live as independently as possible.”
- “...the services he coordinates are too slow and have waiting lists and don’t do as thorough a job as they propose. All this is beyond the care manager’s control.”
- “A clubhouse can be very comprehensive...”
- “We have good care in this county and many agencies and workers who help.”

Representative comments that addressed services from specific community support service components are listed below.

Crisis Response.

- “I would like to be able to talk to my psychiatrist when I phone the crisis line.”

Mental Health Treatment.

- “I have had depression all my life. It has been hell and only wish I could have been stabilized years ago.”
- “I have a borderline personality disorder and alcoholism and I am having a problem with both of them right now and there is no place that treats them at once.”
- “...My biggest problem is not the illness but side effects of medicine.”
- “...more contact with my psychiatrist concerning the effects of my medications.”
- “...I have received excellent health care for treatment of my mental illness diagnosis, schizo affective bipolar.”
- “...because of the help I have received from my local group therapy and from the community support program in xx, I now have a place to live and some new friends.”
- “Closing the MHU at MMSC greatly bothered me. Now I have to go out of town for inpatient treatment. It’s more than an inconvenience.”
- “Learn more about the way I feel taking meds...”
- “...I found since going through the xx system in xx I’m learning more about manic depressive disorder...The staff seems to care about me as a person.”
- “Since I first started getting treatment for my depression almost 4 years ago, I have not relapsed back into my alcoholism and drug dependency. I have a life back after 28 years and I am grateful!!!”
- “I think we should be able to see our psycho-therapist without a psychiatrist present in the building.”
- “If it wasn’t for the community support program worker helping me I probably would have tried to commit suicide again.”
- “I have a borderline personality disorder and alcoholism and I am having a problem with both of them right now and there is no place that treats them at once.”

Income and Entitlement.

- “They take away Medicaid and SSI if my husband makes a certain amount in one month, but they don’t consider that my medication costs over 600 dollars a month which is half his pay.”
- “I am very active at volunteer work but cannot get paid working in the community. If I move where I could get a job the county has the right to take my home, furniture, and car. I am being helped more than ever before, but still have needs.”
- “To try and become self-supporting doesn’t work because the government takes the money away too fast.”
- “The Title 19 spend down is raised every year making the increase in SSDI nil.”

- “From 1992 till now I have been fighting to obtain help from xx county. Because I was single and a veteran no one was willing to help me.”
- “This month Blue Cross-Blue Shield disability review was done; first time since 1980. Rules of BC-BS discourage one from seeking employment as one would lose benefits.”

Protection and Advocacy.

- “...legal rights as a veteran trying to obtain help I have had to hire a lawyer...”

Physical Health and Dental.

- Three respondents reported serious medical problems that required treatment.

Housing.

- “I like xx but I would rather be in a group home so I could have my own bedroom or share a room with one other friend.”
- “I would like to move to my own apartment but need a job/money first.”

Psychosocial Rehabilitation.

- “I have been on the local jobs program waiting list for 9 months now. These services should not be so slow. This is why I am very dissatisfied.”
- “There are no jobs suited for the mentally ill and few employees will work with us...”
- “I need help on voc rehab for college courses and job part-time.”
- “...I had a very difficult experience working and keeping my jobs - of being accepted in society.”
- “There is a grave need for a Clubhouse that could provide many of the services deficient in the community...”
- “The key to my success in dealing with my mental health problem was through self analysis as long as my support systems helped me in that capacity they benefited me.”
- “I am not allowed to have individual therapy and I think I have a right to this service.”
- “I go to day treatment...also go to community support program...When I’m in my apartment in evening I get somewhat depressed.”

Peer Support.

- “I have had a terrible time with relationships of the opposite sex in my case men. I’ve been the victim of crime more than my share of times.”
- “I have problems with loneliness connected with a high level of intellectualization, which makes it hard for me to find suitable companions...”

Identification and Outreach.

- “Transportation is my main problem...”
- “Outreach services are helpful, having a therapist who understands chronic mental illness is very important.”
- “The outreach community program is excellent..”
- “The home visits I receive are very important to me...”

Family Support.

- “I need help with my family but don’t know how to get it.”
- “...my family is not supportive.”
- “[family] still refuse to accept the fact that I have a mental illness...”

Case Management.

- “I have a bad and incompetent case manager. The services offered by my mental health agency were fine, though.”
- “I have asked specifically for many of these services...and am just now connected with a ‘case manager’...”
- “...I would like to have my case manager meet with me once a month, so I can get out on my own.”

Summary of Survey Findings

Service Component Use and Satisfaction. The satisfaction with service components was uniform and over 80% for all components. The reported use of services was more variable and ranged from 95% for mental health treatment to 43% for housing. The proportion of respondents who used and were satisfied was calculated for each service component. Most respondents (87%) reported that they had both used and were satisfied with mental health treatment whereas only 38% of respondents had both used and expressed satisfaction with housing services.

Access to Services

I. Crisis Response. The services with the highest reported access (88% each) were: walk-in crisis support at a CMHC, outpatient psychiatric clinic emergency services, and hospital emergency room visits. The service with the lowest reported access was phone contact with a counselor (55%).

II. Mental Health Treatment. Access to services ranged from 68% for family therapy to 89% for monitoring symptoms of mental illness.

III. Income Support and Entitlements. Access to services within this component was between 82% and 88%.

IV. Protection and Advocacy. Access rates for services within this component were approximately 70%.

V. Physical Health and Dental Services. Access to services ranged from 58% for assistance with smoking cessation to 86% for assistance with prevention of sexually transmitted diseases and AIDS. Access to medical treatment was reported by 85%.

VI. Housing. Access was 96-100% for services in this component except that only 62% of respondents reported help in finding emergency housing when needing it.

VII. Psychosocial Rehabilitation. Service access ranged from 60% for help with finding volunteer work and 83% for supervision or help with managing money.

VIII. Peer Support. Access to services within this component ranged from 71% to 83%.

IX. Identification and Outreach. Access to services ranged from 78% to 86%.

X. Family Support. Access ranged from 55% for identification of temporary caregivers to 84% for education about the illness and medications.

XI. Case Management. Access to case management services was reported to be from 76% for 87% for all types of services within this component.

Service Need

For nearly all of the services indicated within all service components, there was no apparent receipt of unneeded services from the consumer perspective (i.e., services, when received, were reported as needed by 90% or more of the respondents). Exceptions were the following: 78% of respondents who reported receiving help finding emergency housing also reported needing such help (Service Component VI. Housing); 86% of persons who reported receiving identification of temporary caregivers so that family could get away also reported needing such help (Service Component X. Family Support).

Service Utilization

I. Crisis Response. Service utilization ranged from 5% for mobile crisis unit to 38% having phone contact with a counselor. Nearly one third of respondents indicated that they had used the emergency room at a hospital over the past one year period.

II. Mental Health Treatment. Service utilization ranged from 10% for family therapy to 63% for individual counseling.

III. Income Support and Entitlements. Service utilization was between 25% and 50% for all services within this component.

IV. Protection and Advocacy. Service utilization was 26% or less for services in this component.

V. Physical Health and Dental Services. Service utilization was less than 50% for all services within this category. The lowest rates of service utilization (5%-8%) were reported for help in abstaining from substances (alcohol, drugs, or cigarettes) and for assistance with pregnancy prevention.

VI. Housing. Low rates of service utilization (22% or less) were reported for housing services.

VII. Psychosocial Rehabilitation. Rates of service utilization were 35% or less for all services within this component. The lowest utilization rates were reported for help in finding volunteer work (12%), help with completing education (14%), and assistance in maintaining personal hygiene (14%).

VIII. Peer Support. Rates of service utilization were between 23% and 38% for all peer support services.

IX. Identification and Outreach. The service with the lowest reported utilization rate was outreach services to individuals who decline a formal treatment program (9%). The highest rate of utilization (44%) was reported for information about service availability and referral to agencies.

X. Family Support. The service with the lowest reported utilization rate was identification of temporary caregivers so that family could get away (5%); utilization of referral to family therapy groups was also low (8%). The highest utilization rate for services in this category was 44% for education about the illness and medications.

XI. Case Management. Case management services were utilized over a one year period by 26% to 56% of consumer respondents.

Study Conclusions

1. The proportion of consumer respondents who indicated satisfaction was high (over 80%) for all service components.
2. The reported use of service components by consumers was variable and ranged from 95% for mental health treatment to 43% for housing.
3. The crisis response services with the highest reported utilization (88%) were also services which would be expected to have the highest cost, e.g., outpatient psychiatric clinic emergency services and hospital emergency room visits. The service with the lowest reported access, phone contact with a counselor (55%), would most likely have the lowest expected cost.
4. Access to all types of services within all service components was greater than 50%.
5. With only two minor exceptions, there was no apparent receipt of unneeded services from the perspective of the consumer (i.e., services, when received, were reported as needed by 90% or more of the respondents).
6. All services within all component categories were utilized by less than 50% of respondents except for five services within the mental health component (utilization rates between 51% and 63%) and one service by case managers (monitoring of condition by case manager, 56%). The highest utilization rate reported by consumers was individual counseling (63%).

Study Limitations

Survey respondents and their perceptions about services may not be representative of all consumers in all parts of Iowa. Respondents are describing their own needs and preferences for services which are related to illnesses that are different from one another. Furthermore, respondents do not receive services from the same providers and agencies. This survey provides an assessment of community support services by 269 persons who have a serious mental illness and who live in Iowa. Limitations of the present study should be considered in its interpretation and application.

1. *Bias of ascertainment.* Subjects who were referred by case managers and community support program directors may have been more likely to report higher service use and a more favorable assessment than subjects who were referred by the Iowa Coalition and the Alliance for the Mentally Ill of Iowa (AMI). This may have been especially true if they received help in completing their questionnaire from their case manager or another service provider. One hundred twenty one respondents (45%) reported needing help in completing the questionnaire. Help completing the questionnaire was from the following: CSP staff (55%); case manager (11%);

spouse/significant other/friend (11%); not specified (9%); professional staff (9%); and parent (6%).

2. *Non response bias.* Of the 1189 consumers identified as potential survey respondents, only 269 (23%) completed and returned their questionnaires. Survey respondents who completed and returned their surveys may have been different from those who did not by a non-random self-selected process. For example, subjects who were referred by case managers and community support program directors may have been more likely to complete their survey instruments and their responses might have been different from respondents referred from other sources.

3. *Definition of variables used (access, service need, and utilization) are not precise nor are they comprehensive.* Service access as defined by this study is likely to provide an overestimate of access given that it measures the proportion of services received only by those who perceive a need for that service. It does not take into account persons who may be too ill to realize that they need a service and hence, seek its use. Furthermore, people may be more likely to perceive that a service is needed only if they are able to receive it (or it is offered to them). Service need, defined as the proportion of respondents who indicated that they needed a service out of the population who indicated that they had received it, is only a crude estimate of undesired service. It does not address the appropriateness of services that are received, regardless of consumer perception of need. An unknown proportion of consumers may assume that if they receive a service, it is needed. Finally, service utilization, defined as the proportion of respondents who indicated that they had both needed and received a given service out of the population of all survey respondents does not take into account the availability of service. A service that is readily available may be overutilized and a service that has limited availability will be underutilized. This variable does not provide any information regarding service appropriateness, i.e., its effectiveness on the treatment for any individual or groups of individuals.

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